

Article

An Exploration of the Practical and Ethical Issues of Research Using Multi-Visual Methods with Children Affected by Chronic Pain

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Abstract: This paper intends to encourage further reflection on the research methods and approaches used to enhance the voices of children with chronic conditions. Visual methods (e.g., ‘draw, write, and tell’ and photo elicitation interviews) have been described as the most appropriate ways to develop research with children as they allow room for children to share their lived experiences in their own terms and to actively participate in the research process, by giving them the opportunity to act as co-researchers. In fact, the use of these methods also contributes to empowering children and mitigating the power differences that exist between the adult researcher and young participants. Drawing on an ongoing study on the experience and management of chronic pain in childhood, this paper provides insights on the usefulness of using these multi-methods to address (potentially) sensitive topics with a (potentially) vulnerable group. The ethical and methodological challenges faced by the researcher when conducting research with ill children in the healthcare context are addressed. The paper looks at the dilemmas of studying chronic pain in childhood and highlights the ways in which multi visual methods can help children in the meaning making of chronic pain.

Keywords: social research; visual methods; children; sensitive topics; vulnerable populations; chronic pain

1. Introduction

There is a lack of knowledge about the daily living experiences of children with chronic pain, and what is known focuses either on children and families’ encounters with medical professionals [1] or on the impact that caring for a child (i.e., someone who is under 18) with chronic pain has on family relationships [2]. There is a need to understand how children and their families live with and manage chronic pain. The broader qualitative study discussed within this current article intends to fill this gap and offer insights on the experience and management of chronic pain in childhood by listening to the voices of children [3]. Although it is known that children with chronic pain have important knowledge of their affliction [4], perceptions and beliefs about chronic conditions have mostly been collected from healthy children [5–7]. Pain is difficult to communicate through language [8], therefore we believe the use of multi-visual methods can enhance our ability to understand the experience of chronic pain in children by enhancing their agency and right to participate in research on matters concerning their health and well-being [9].

Because of its inherent nature, chronic pain is a sensitive topic which can evoke powerful emotions and therefore be emotionally demanding for the researcher and research participants [10,11]. This is amplified when vulnerable subjects such as children with chronic conditions are involved. Children with chronic pain might be considered a doubly vulnerable population as not only do they lack the ability to make some personal life choices and personal decisions due to their

age (e.g., about their diet or schedules) [12]; but they might also experience diminished autonomy due to their chronic pain [13]. By saying that children with chronic pain are a doubly vulnerable population, we are not suggesting that children's agency should not be recognized. The right of children with chronic conditions to participate in research should not be undermined due to their double vulnerability [14]. This assumption draws upon the belief that children are able to make sense of their chronic pain and should be offered the chance to express themselves in their own terms [15]. We hope that the use of multi-visual methods, namely through the use of drawings and photographs, will make it easier for children to express what it is like living with chronic pain [16–18]. The focus of this article is to describe the ethical and practical aspects of using multi-visual methods for conducting research on children's lived experience of chronic pain.

2. Vulnerability and Sensitivity in Social Research Involving Children

There is an extensive debate surrounding the ethics of social research with children. However, it is possible to reduce the main arguments to one question: How different are children from adults? The answer to this question may involve words such as 'vulnerability', 'incompetence', 'irresponsibility', and 'powerlessness', referring to the idea that children are not as capable as adults of making sensible and rational decisions and of providing valid sociological data [19]. In addition, childhood can be interpreted as a phase in which the child is 'under construction', a phase that culminates with the arrival of adulthood ('becoming child'), as opposed to the idea that the child is a social actor, who actively participates in its development and has valid ideas and opinions ('being child'), which implies that during this transition phase, the child lacks a set of universal skills that make it impossible for him/her to be taken seriously [20].

It is crucial to explore children's perspectives on issues that concern them or are close to them. Thus, in this article, children are considered to be active social agents capable of thinking and reflecting on their condition and what surrounds them [21–24]. Now, defending children's participation in social studies does not imply disregarding the (potential) vulnerability of these actors. In fact, there is a set of characteristics that can place children in the category of vulnerable subjects, such as being subject to the authority of others [25], as well as their lack of ability to make some personal life choices and personal decisions due to their lack of life experience [12]. In addition to this (potential) 'structural' vulnerability, due to its transversality to child status, it is important to mention a second level of vulnerability related to the existence of a health condition (i.e., chronic pain) that may restrict their autonomy [13,25].

If, on the one hand, the use of the concept of vulnerability makes it possible to categorize the children involved in the present study, on the other hand, it is a concept that has been challenged precisely because of the broad character it can assume in relation to certain social groups [26]. Thus, it is assumed in this paper that not all children with chronic pain are equal, but it is also assumed that there is a strong likelihood that they will be subject to a double level of vulnerability, even if it is contextual (depending on the subject and the environment). If we add to the subject's vulnerability the topic's sensitivity, the research becomes significantly more complex. Like the concept of vulnerability, the concept of sensitivity also raises questions: What constitutes a 'sensitive' topic? What are the requirements? In a similar way to the concept of vulnerability, the concept of 'sensitive' topic is also contextual, as sensitivity varies according to the situation and the participants, who have their own system of beliefs, values, and cultural norms that guide them [27]. The sensitivity of the topic is usually expressed through the manifestation of certain emotions (e.g., anger, frustration, fear), not only for the participants but also for researchers themselves [10,11].

Conducting social research that focuses on (potentially) vulnerable subjects and on (potentially) sensitive topics can pose several challenges in relation to the recruitment process, the process of access to the research field, and the process of obtaining informed consent, for example [23]. In order to overcome these and other challenges, it is important to incorporate awareness of vulnerability and sensitivity into the research design by selecting methods to address these (potentially) challenging aspects. In the case of social research with children, it is possible to find different types of specific challenges related, for example, to power differences, parental gatekeeping, and children's

competences. Faced with these challenges, Kutrovátz [28] states that the combination of traditional and innovative techniques allows the creation of strategies to minimize these challenges.

In this paper, we will explore the ‘draw, write, and tell’ technique, as well as photo-elicitation interviews as methods that give voice to children with chronic pain in a non-invasive way and that value the perspective of these actors by using a specific language adapted to their reality. Using drawings and photographs gives children the ability to communicate in a way that is familiar and close to them [28]. In this way, children are given the opportunity to approach the topic of chronic pain in a way that makes them feel comfortable, portraying through drawings and photographs, their medical condition on their own terms. In addition, the ‘draw, write, and tell’ technique and the photo-elicitation interviews allow a change in the usual power dynamics that are established between researcher–researched. It was thought that the use of these methods would make the relationship between adult researchers and younger participants more egalitarian [9], although absolute ‘ethical symmetry’ [29] might, to a certain extent, not always be achieved due to the (potential) vulnerability of the participants and the (potential) sensitivity of the topic under study. These and other aspects are discussed in the following sections.

3. The Everyday Life of Children with Chronic Pain: What We Know and What We Really Need to Know

While there is some work on children’s experiences of post-operative pain [30] or cancer-related pain [31], little has been said about the experience and management of children with chronic pain and their parents. For this study, chronic pain will be defined as that which lasts more than a month beyond the normal course of an acute disease, healing, or injury [2]. The experience of chronic pain refers mostly to headaches, followed by recurrent abdominal pain, back pain, and musculoskeletal pain [32]. Despite its prevalence (20% to 35% of children and adolescents worldwide suffer from chronic pain), the condition is under-researched and, due to a lack of clinical guidelines, many children do not receive appropriate pain management [33]. This can have severe social, psychological, and physiological consequences for children; the comprehension of their embodied and living experiences is essential in order to develop proper pain management strategies and therefore to enhance their overall quality of life [30].

Healthcare professionals’ beliefs and misconceptions or even lack of knowledge on pain management in childhood tend to compromise adequate pain relief and lead to suboptimal care [34,35]. The quest for a diagnosis and treatment tends to be characterized by frustration and despair, as most of the time healthcare professionals are unable to identify a physical cause and, thereby, tend to blame the child or the family for the condition [1,36]. Indeed, the experience and management of chronic pain by children and parents tends to be marked by uncertainty due to the contested nature of chronic pain [37]. The complexity of assessing pain in children, particularly chronic pain, might be one of the reasons that explains the lack of effective proper pediatric pain relief [35]. Pain has been described by parents as being one of the most challenging and difficult aspects of caring for a child with a chronic condition and they often complain about the lack of clear guidelines to inform and help them effectively manage their child’s pain [30].

There is a lack of knowledge about the daily lives of children with chronic pain, and what is known mainly arises from children who suffer from chronic conditions. Chronic conditions have a disruptive effect on children’s lives and on the lives of their parents [38]. Parenting children with chronic conditions might also be characterized by uncertainty associated with the timing of symptoms [39]. This might lead parents to be in a state of constant alert for their children [40]. Furthermore, it is not only parents who are affected by the chronic condition of their children, research has shown that siblings assume caring responsibilities when a brother or sister suffers from a chronic condition [41]. Chronic conditions can also be detrimental to family relationships as the healthy child may feel the need to compete with the child with a chronic condition for equal parental attention [42]. Notwithstanding, this body of literature has shown the challenges of living with a pediatric chronic condition in the family setting; how children live with and manage chronic pain in their daily life has not been explored in detail. The purpose of the study within which this article

draws on and its methodological approach will be outlined in the next section.

4. Methods

There is little understanding of the needs of children with chronic pain and the needs of their parents [2], which can be explained by the scarcity of information available about living with chronic pain in the family context [43]. The ongoing study, within which the current paper is based, intends to fill this gap by providing insights into the family experiences and management of chronic pain in childhood. The key research questions that this ongoing study intends to answer are: (i) How do children and their parents experience living with chronic pain? (ii) What meanings do children and their parents attribute to the condition? (iii) In what ways do children and their parents manage chronic pain? (iv) How does the condition shapes family practices? Portugal offers an interesting context in which to explore these issues as it has been marked by a scarcity of information on pediatric chronic pain and of resources available to children with chronic pain [44].

A qualitative approach will be developed. A key challenge when conducting research on sensitive topics with children is the recruitment process [23], since access to children is very controlled by various adults (e.g., parents, teachers, and health professionals) and entities (e.g., schools and hospitals) [45–48]. It is expected that the recruitment of participants through a multidisciplinary chronic pain unit, located in a general hospital in Lisbon, Portugal, will help to mitigate such challenges. This might be because parents tend to feel safer when the recruitment contact is made through a known professional and/or institution and they therefore may be more likely to consent to the participation of their child [49]. As chronic pain is a sensitive topic, we expect that not all children who are being followed in the multidisciplinary chronic pain unit will be willing to participate in our qualitative study. Therefore, the sample will be constituted by twenty children, aged 7–10 at the time of recruitment, who suffer from chronic pain. We will target this age group because children are able to relate to pain physically and begin to have an awareness of their body [50]. The sample size has been established based on convenience criteria defined in informal conversations with the healthcare professionals of the chronic pain unit prior to fieldwork.

Prior to recruitment and data collection, ethical approval will be obtained from the general hospital, where the participants will be recruited. Ethical approval has been granted by the host research center of the research project. Written informed consent will be obtained from the children and one of their parents, with the understanding that participation will be voluntary, that they will have the right to refuse to participate in the completion of any task or to answer questions, and to withdraw from the study at any stage without consequences. Their right of privacy, confidentiality, and anonymity of data will be respected. A consent sheet with information about the aims of the study, what will be expected from them, and their rights, if they decide to participate, will be provided. An age appropriate information sheet will be given to children [41] and consent will be obtained from children and their parents separately [19]. It is hoped that this dual process of consent will guarantee children's autonomy to participate in research, as well as recognize the parent's responsibility to ensure the protection of their child [51,52]. A social constructivist thematic analysis has proposed by Braun and Clarke [53] will be employed. The themes will thus be derived deductively from the different sets of data collected.

5. Results: Employing Multi-Visual Research Methods for Studying Children's Experiences of Living with Chronic Pain

Within the research context, one of the main challenges was how to address children's agency. This is premised upon the belief that children are capable of making sense of their living experiences and should have a voice on matters concerning them [15,54]. The United Nations Convention of the Rights of the Child (1989), namely Article 12, is at the heart of this belief. The following sections intend to show how the use of multi-visual methods (i.e., 'the draw, write, and tell' technique and photo-elicitation interviews) would enhance children's agency by offering them more autonomy and control over the research process [9], as well as to demonstrate how these methods might be helpful to overcome the difficulties that might arise from studying a chronic condition like chronic pain.

5.1. The 'Draw, Write, and Tell' Technique

Drawing is a fun, therapeutic, and educational activity that enables children to develop their ability to imagine and communicate [55]. In addition, drawing enables children to express experiences that may be more difficult to describe otherwise (e.g., through language alone). Drawing also gives children time to reflect on the questions they are asked and the message they want to convey, which leads to a different level of reflexivity [56]. The 'draw, write, and tell' method has been traditionally used in the fields of psychology and education. More recently, this method was used in other fields of knowledge, such as sociology, and it has enabled, for example, an understanding of how children look at health issues [55,57–59].

The 'draw, write, and tell' method [57] will be used for children to complete their first task and will take place in the chronic pain unit in a private room. Children will be asked to think about what chronic pain means to them, draw it on A4 blank paper using crayons, write their thoughts on it, and then tell the researcher about it. The children will be asked to not draw their name or the name of their family members or friends to protect their privacy and confidentiality [17]. Using the picture as background, the researcher will be able to ask the child questions about the topic. After the conversation, the researcher will take a photo of the drawing and will give the original to the child as a way of thanking them for their participation [60] and safeguarding the 'ownership' of the drawing [61]. It is important to give children something in return, something that may even provide parents/family members with some clues about the research (e.g., the questions posed) and about how children see and interpret their own condition.

The 'draw, write, and tell' method will enable us to make children's interpretations key in data collection [57]. Indeed, it was thought that the danger of misinterpreting what the children want to express would be overcome by giving them the chance to interpret what they have produced [19]. The child will be positioned as a participating subject in the research process [16,62], through an approach that might be familiar to them as most school age children (e.g., 7 to 10 years old) produce drawings, write, and talk about them at school or at home for fun [63–65]. The 'draw, write, and tell' method will enable the researcher to work *with* children instead of the traditional approach of working *on* children [64] and we believe that this would help to diminish power differences between the adult researcher and young participants [17]. In fact, this method contributes to empowering children, making them co-researchers, i.e., agents capable of producing and interpreting knowledge about themselves [29]. In addition, the opportunity to approach sensitive topics through drawing allows the child to talk about their condition indirectly, for example, by choosing to assign their characteristics and symptoms to a character in their drawing.

The sensory and embodied experience of chronic pain may be shared through the 'draw, write, and tell' method as children might be able to communicate their lived experiences whether through drawings, verbally, or using written words. In this sense, and as referred to by Pope and colleagues [55], (p. 43): "Young children are capable of expressing subjective concepts such as their experiences of pain". The use of this technique has been proved to be successful for studying children's beliefs of health and illness, in particular, of chronic conditions like cancer [61]. The child will be positioned as the 'expert' of the chronic condition in the sense that they would be invited to interpret their drawings orally or in writing [63]. In addition, the researcher will also take field notes that incorporate unspoken behavioral aspects (e.g., expressions and body language); in this way it will be possible to add elements to the research that can give clues about what is said and what is not [55]. Through drawings, children might express issues or thoughts that they might not want to express through language, which might precipitate negative emotions that the researcher must be prepared to deal with [17,61,63]. It is expected that the experience of the researchers in conducting research with vulnerable populations on sensitive topics will mitigate any negative feelings or situations that could emerge. Nevertheless, an agreement will be made with the psychological team of the chronic unit where fieldwork will take place that, if needed, they will provide emotional support to our young participants.

5.2. Photo-Elicitation Interviews

At the end of the first task, the researcher will give each child a digital camera and an instruction sheet explaining what the child should do with the camera and how to use it. Children will be invited to use the camera during approximately a one-month period to take photos on three topics: (i) How I live with chronic pain; (ii) How I manage chronic pain; (iii) How I think my family and friends see my chronic pain. The photo-elicitation interview with children will be scheduled one month after the cameras had been given to them. Photo-elicitation interviews have been found to be particularly appropriate for studying everyday life and therefore it shows the potential for studying the experience of chronic pain in childhood [66]. Indeed, through photography, children will be able to capture and describe the sensory and embodied experience of chronic pain and the impact that it has on their daily living. It was thought that the taking of photographs would be an enjoyable and fun experience for children, offering them a certain degree of control over the research process [16,67]. As with the 'draw, write, and tell' technique, this method also promotes child empowerment, allowing them to make decisions about the content they want to create and discuss [68].

Photographs have been described as a powerful instrument as they might evoke memories, emotions, and reactions that might be difficult to capture through words in purely verbal interviews [69]. Through photographs children might be able to display issues that otherwise would be invisible or hidden albeit important for understanding the experience of chronic pain in childhood [18]. It is believed that photographs will more accurately reflect the children's embodied and lived experiences than other methods such as drawings [9]. It is hoped that inviting children to take photographs in their own environment will help, to a certain extent, to minimize the sensitivity of the topic under study [23]. While it could be argued that photographs will enable children to construct a particular story of themselves, it will be expected that the framework established by the researcher at the beginning of data collection, about what topics should be covered by the children in their photographs, will help to minimize this risk [66]. In addition, photographs are "socially produced artefacts" and thereby offer a "partial and incomplete" representation of children's pain lived experiences [70] (p. 100).

The photographs taken by children will not be analyzed but instead will serve as a visual prompt for them to talk about the topics they were asked to photograph. The children will be asked to describe the photographs and an interview schedule will be used by the researcher to ensure that the same topics will be covered in all the interviews [41]. The topic of chronic pain, due to its inherent sensitivity, will only be introduced by the researcher at the end of the interview in order to give the child enough space to feel secure and comfortable enough to talk about it [71]. Nevertheless, it is believed that having a visual prompt such as a photograph will stimulate children to talk about their living experiences [18,67,72]. This could be a cathartic and/or therapeutic experience for children, as the chance to talk about their living experiences might provide them an opportunity for emotional release, albeit we might consider this a non-anticipated and beneficial effect of the study and the methods employed [10]. In a similar way to Birch and Miller [73], we use the term therapeutic to refer to an emotional process by which children might reflect and come to an understanding of their lived experiences.

The photo-elicitation interviews will, preferably, be conducted in the child's home as it has been found to be the space where children tend to feel more comfortable [74,75]. When interviewing children in their own homes we need to be flexible as we might have to negotiate some compromises in relation to the space where the interviews will be held, unlike what could happen if interviews were conducted in an institutional setting such as the hospital. Indeed, we are aware of the impossibility of controlling the environment surrounding the interview, where the existence of noise and the lack of conditions (e.g., the absence of a table, lack of space, or the arrangement of furniture) might condition the interaction with the child [76]. We will also try to seek a balance between the professional researcher and 'good guest' status [77]. Parents will not be present during task completions in order to give children enough space to express themselves in their own terms [74], unless the child expresses a wish for them to do so and will feel safer in their presence. Nonetheless, given the unpredictability inherent in conducting interviews in children's homes, we anticipate some difficulties in managing the presence of adults [76]. All these issues will have to be managed as they

arise, and we will use our ‘moral and emotional judgment’ [78].

Before the photo-elicitation interview takes place, although written informed consent of children will be obtained at the beginning of the research process, the researcher will ask children if they still want to participate. We hoped that ‘process consent’ [79] will enable children to have control over research participation [80]. We will be prepared for the possibility, particularly as we will be working with children with chronic conditions, of informed dissent (i.e., “the capacity and opportunity to ‘say or express no’” [81] (p. 152) through verbal avoidance or changes in body language, and thus will facilitate the child’s non-participation in every stage of the process without compromising their well-being [17]. We will again use our own ‘moral and emotional judgment’ to interpret situations and responses [78] in order to take the best ethical decisions to protect the child [82].

At the end of the photo-elicitation interview, we will print a set of photographs and give them to each child as a way to thank them for their participation [60]. Although the consent of children would be obtained regarding the use of the photographs taken by them in research outputs and future publications for over 15 years, it is hoped that this will, to a certain extent, safeguard the ‘ownership’ of the photographs taken by the children [70]. The cameras will be offered to children after the photo-elicitation interview by way of thanks for their participation.

6. Discussion

There is growing recognition of the importance of giving voice to children in social research [83,84], particularly in matters concerning them [48,85,86]. Visual methods have been described as the most appropriate way to develop research with children, due to their flexible and interactive nature [66], as well as potentially enabling active participation of children in the research process [87]. Indeed, these methods are child-centered and might allow room for children with chronic pain to share their lived and embodied experience in their own terms [88]. The use of techniques which are familiar to children such as task-based methods are considered the best way to create a safe environment where children feel comfortable speaking with a non-familiar adult [3].

Researchers need to be prepared for the everyday difficulties of working with vulnerable subjects (e.g., children) on sensitive topics (e.g., chronic pain) which might emerge across the research process and cannot be anticipated [89], related to the interactions, the expectations they generate, or the spaces where they occur [77]. In fact, this type of research incorporates a high level of unpredictability which leads the researcher to adopt anticipatory and situational strategies. Reflexivity or ethical mindfulness [80] might help to overcome the “everyday ethical issues that arise in the doing of research” [89] (p. 263).

Working with vulnerable subjects on sensitive topics might be an emotionally demanding experience for researchers, who also need to be well prepared for dealing with the emotions of participants, as well as their own emotions [90,91]. Researchers need to be good communicators and be able to establish a trustful relationship with the participants [92]. A self-reflexive approach might be helpful to deal with the emotionality of the research encounter [93,94]. Within this context, emotionally sensed knowledge, i.e., the “knowledge sense *through* or *by* emotion” [95] (p. 748) might be key for enhancing researchers’ understanding of the phenomenon under study [96]. Indeed, the acknowledgment of emotions might facilitate researchers’ understanding of potential sensitive topics from the point of view of populations considered vulnerable [97].

7. Conclusions

Any research with populations considered vulnerable on potential sensitive topics might be bound up with ethical and methodological pitfalls [49]. This article has described some of the challenges of studying the embodied and lived experience of chronic pain by children in the family setting and how the use of multi-visual research methods might be helpful for overcoming such challenges. While it is possible to anticipate some of the challenges that may arise from this type of research, there are several aspects that emerge from it which are unpredictable [89], leading to the need to adopt a critical and vigilant stance regarding the research practices and their implications. This article suggests that the adoption of self-reflexive strategies might prepare researchers for

dealing with the practical and ethical dimensions of the research [98] and illustrates how reflexivity is a powerful “methodological tool” [99] (p. 302).

Although the present article is not based on the analysis of concrete empirical data, the reflections presented are framed by the mobilized literature and the authors’ experience in participating in research projects on sensitive themes and involving populations considered vulnerable. Overall, this article adds to the literature by demonstrating the complexity of developing research with children (i.e., a vulnerable population) on chronic pain (i.e., a sensitive topic); suggesting, through practical and ethical dilemmas, the importance of adapting research procedures to the actors and the context in which the interaction occurs even at an early phase of the research; by enhancing the procedural character that this type of research assumes, in the knowledge that vulnerability and sensitivity are present in all phases of the process. It therefore highlights a less visible aspect of the research process itself and the importance of adopting a critical and reflexive approach.

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